What do People with Developmental Disabilities Need?

- **Food, Shelter, Clothing (not Medicaid except in facilities)**

Since this is not within the realm of Medicaid who is responsible for these basic needs? In addition to Disability Cash Benefits (SSI/SSDI) the State (IDHW) is to provide a supplement (AABD) and SNAP, to meet them. When this level of need is not met, all of the other areas are affected. There should be regular monitoring of these needs by someone (Case manager?)

- **Medical care**

At the annual medical physical exam, the primary care provider should be expected to answer a set of questions which will assess the person's state of health, whether it is improving or deteriorating, what should be done to improve the person's health and recommendations for changes or additions to the person's plan. This information should be collected in a way that is both useful to planning for the person and can produce data for systemic study. This process can be integrated in a "medical home" model, the assessment and the "person centered planning" process. Easy access to services which enhance health or prevent disease should be valued. Smoking cessation, diet and nutritional assistance, exercise programs and immunizations should be included.

- **Safety (protection and monitoring)**

Safety concerns include issues of the safety of the person and the safety of others when a person's behavior poses a risk to others. The Assessment should include an assessment of risk (this is required systemically by CMS). Risk should be assessed from all perspectives including environmental risks in the person's living arrangement, risk from abusive roommates, self harm, and risky or naïve behaviors which require monitoring or supervision. It also includes the need for monitoring of dangerous or threatening behavior which affects the safety of others in the home or community. Risk assessments and the planning to address risks are highly individual and dependent as much on the unique factors of a person's environment and situation as they do on the person's characteristics. It is impossible to rely on numerical scores from skill assessments to measure the risk much less devise strategies to lower the risk. Providers and participants need flexibility to be creative and responsive to situations which pose a safety problem for the person, their roommates, the direct support provider, or the community.

- **Living Skills/Adaptations/ Personal Care**

Not all problems with accomplishing activities of daily living are caused by skill deficits. In the traditional "therapy" model, skill acquisition was the main (if not the only) focus of Medicaid services. Prior to the dominance of Medicaid, Idaho's Child Development Centers, and later

"Adult and Child Development Centers" were explicitly education and training programs. In order to bring the services under the purview of Medicaid, they became "therapy" programs. The emphasis on skill acquisition has sometimes created a perverse incentive to try to address needs for personal assistance, as if they were needs for skill acquisition. Someone whose motor control would never allow them to dress themselves (or brush their teeth bathe, etc.) would receive years of "training" in small parts of tasks related to dressing, etc. , with minimal progress and no practical value, **except that** while "running the program," the person got dressed. The actual need could have been more efficiently addressed by simply providing dressing assistance without the fiction of "improving dressing skills." A program focused on giving the person choice in what they wear and learning to direct the personal assistant on how to help them with dressing would have been much more useful. We should plan to meet a person's need for accomplishing activities of daily living through any appropriate combination of skill development, supportive services, assistive devices, occupational therapy and whatever else would work for the person. The main issue should always be "How will this person eat, dress, bathe, exercise, use the bathroom, cook, pay bills, clean house, etc.?" and not "What skill does this person lack which we can write a program for?" Developmental therapy has been shaped by the idea that the only permissible (or reimbursable) activity is structured skill building using some form of Applied Behavior Analysis.

Skill building continues to be a major need for most people with developmental disabilities. Acquiring or improving skills for activities of daily living (and instrumental activities of daily living if you make that distinction) should be a high priority, when appropriate, because it leads to greater independence and integration into community life. As circumstances change people with DD will need new skills to adjust to new challenges and opportunities. Even aging and retirement require skills and adaptations which may create a need for more skill building.

Skill building can sometimes be served by physical, occupational or speech and language therapy. Other times, powerful training techniques such as applied behavior analysis are needed. Sometimes only assistance from a patient and caring person is needed to acquire the necessary skill. The person centered planning process is the best place to determine the mixture of training and support that will meet this area of need.

- **Behavioral Problems / Mental Health**

  Although serious maladaptive behaviors have been addressed as training needs, I have grouped them with mental health needs for purposes of this discussion. For many people with DD, maladaptive behaviors have been addressed through some form of applied behavior analysis, unless the person has a dual diagnosis of DD and mental Illness. Once again it is possible that our categories are interfering with our ability to take the most effective approach to the person's needs. ABA therapy is a proven method for reducing the frequency or intensity of targeted behaviors, but it is not the only one, nor is it always the best approach. Medical,

psychiatric, communication, and psychosocial interventions are also evidence based approaches which can be equally or more effective in certain circumstances. People with a dual diagnosis, of course, need access to adequate mental health and psychiatric rehabilitation services.

- **Employment**

  Wait for final product from "Employment First" and Review.

- **Socialization / Recreation / Leisure activities**

  Being integrated in a community requires more than living in a neighborhood. Actual activities in typical community settings with interactions with other members of the community, in typical settings based on common interests and preferences, is a necessary part of our vision. Supports and services which enable this activity must be a key component of each person's plan. Accountability of providers for community integration activities should also be built in to the system. Although Medicaid does not pay for "recreational" activities, it can and should pay for the communication, and social skill building needed for successful community integration. Habilitative Supports in the children's program demonstrates how such supports can be part of a Medicaid program and a permissible service in a "bundled" system.

- **Transportation**

  Transportation is an overarching concern which is essential for satisfying all of the above needs.

- **Protection of Rights/Choice/Self Determination**

  Choice, self determination, and protection of individual rights must be part of every aspect of the process of planning and implementing a system of services and supports. It must also be measured and evaluated in every individual's case.